



Office of the Public Advocate

Accommodation models discussion paper

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Purpose of this discussion paper

Whilst the majority of people with an intellectual disability have never lived in a large institution, the closure of Kew Residential Services, where 462 people currently live, offers a significant opportunity to review the range of accommodation services available to meet the support needs of people with an intellectual disability. The Office of the Public Advocate (OPA) currently provides advocacy for 116 residents of Kew, who have no significant family involvement.

To help the OPA develop its position on what should be a suitable range of accommodation and support options for people with disabilities, OPA undertook a literature review. This literature review has started by focusing on the benefits and disadvantages of residents living in villages, clustered housing and individual group homes. This discussion paper summarises the major findings of the relevant Australian and overseas research evidence found so far. (It is acknowledged that little attention has been paid to research on supported living).

Research issues

The quality of life of people with a disability, whether they are living with family, in an institution, a village, a group home or independently, is affected by more than just their accommodation arrangements. Many factors affect the quality of life of us all. This presents a challenge to research to identify those aspects of accommodation and support services, which are the key determinants of the quality of life experienced.

This research considers there to be fundamental elements essential for any accommodation and support system. Services should be focused upon the needs, wishes, desires and aspirations of the individual with a disability and should be structured in a way, which allows them to respond to changing individual needs. To achieve this, adequate levels of resourcing, appropriately trained and supported staff and access to a wide range of vocational and recreational opportunities are crucial. Planning needs to occur in a collaborative way with family, friends and advocates. Examples of good accommodation services may reflect such factors, as staffing levels relative to support needs, quality of staff, and the availability of programs and facilities. The literature review therefore sought research which tries to take account of the range of possible contributing factors; attempting to identify causative differences, not just associations.

In this respect a study by Emerson et al (1999) is important as it adopted methods to ensure that 'like by like' comparisons were made between different types of accommodation.

Definitions

In reviewing the literature a wide range of accommodation arrangements are called "villages". These include:

- ◆ Villages, which house people with an intellectual disability and staff only.
- ◆ Villages, which have a mix of people with and without a disability. e.g. Camphill
- ◆ Villages which have a mix of types of accommodation eg Acorn.
- ◆ Villages, which have facilities, used by people from outside the village e.g. Stewarts (and all those with retail outlets in the village). (Holmes, 2001, 2002)

It is important to note that many of these villages emerged from strong community based support or philosophical or religious beliefs such as Rudolph Steiner.

In reporting the findings of the research, this discussion paper is to some extent bound by whatever definitions are used by the authors of those studies. However, as far as possible, this paper tries to consistently apply the following definitions:

A **village** is a number of living units solely for people with a disability or support staff on a single site grouped around some shared central facilities, with a common boundary. The actual size of these villages can vary significantly.

A **cluster** is when accommodation for people with a disability is sited so as to be close to (less than 10 minutes walk) other accommodation for people with a disability but is otherwise amidst accommodation for people without a disability.

Dispersed housing is accommodation for people with a disability located amidst accommodation for people without a disability and without regard to the location of accommodation for other people with a disability.

In the Australian context Community Residential Units and supported living arrangements would generally come into the category of dispersed housing, but there are examples where the close proximity of other people with a disability has resulted in clustered accommodation. Facilities like Plenty Residential Services represent a village style of living. In terms of some of the important overseas literature, Emerson et al (1999) make a distinction between villages run by non-government organisations (which they call non-government villages) and those run by the National Health Service (which they call residential campuses).

This literature review has focused on the following key areas:

1. Quality of care
2. Community integration
3. Safety
4. Costs.

The health services available to residents in different types of accommodation is another issue of importance with numerous reported instances of failure of care, including of people in health institutions. . Much also needs to be done to improve the health systems understanding of disability. However, these issues have not been explored as part of this paper.

1. Quality of care.

Evidence was sought to explore the possibility that the larger size of villages may result in more institutional treatment of residents and lower levels of resident satisfaction.

Four measures have been developed to reflect the extent of individual versus institutional care: block treatment, depersonalisation, rigidity of routines, and social distance (Emerson et al, 2000: 85). By all four measures, residents in NHS villages received the most institutional type treatment. Significantly higher levels of block treatment and depersonalisation were found in non-government villages than in dispersed housing schemes, although significantly higher levels of rigidity of routines were found in dispersed housing schemes than in non-government villages. There was no significant difference between non-government villages and dispersed housing in the social distance between staff and residents (Emerson et al, 1999: 31).

The less individual treatment in non-government villages is despite the finding that residents in non-government villages had significantly more adaptive behaviour skills than those living in dispersed housing schemes, who, in turn, had significantly more skills than residents of NHS villages. Emerson's study found a tendency, in all types of accommodation, for people with more severe disabilities to be supported in a more institutional manner (Emerson et al, 1999: 23,31).

Emerson et al (1999) conclude that NHS villages “are of significantly poorer quality than community-based dispersed housing schemes on a wide range of measures of benefits”, while comparison of non-government villages and dispersed housing

“suggests that both forms of provision may be associated with particular patterns of benefits.” (Emerson et al, 1999:110 & 111)

The Emerson study thus seems to indicate that accommodation arrangements as such are of less importance in determining whether care is person centred or institutional than factors such as who runs the accommodation, quality of staff etc.

In regard to satisfaction levels, many studies (Emerson et al 1999:111) note that it is common for research to find that both residents and relatives express high levels of satisfaction with all existing arrangements and that discrimination is more likely when people can make comparative judgements.

Emerson's study asked residents of non-government villages and dispersed housing about satisfaction with 7 aspects of their lives: their home, their day activities, their social and recreational activities, amount of choice, friendships and relationships, the support received and levels of risk. No significant differences between the two groups of residents were found in any of the 7 aspects of their living (p78). Relatives who were in contact with residents were also asked to assess various aspects of support arrangements

and there were no significant differences in the satisfaction levels of relatives of people in NHS villages, non-government villages or dispersed housing (p88).

A subsequent study of resident satisfaction with the same 7 aspects, however, found that residents of non-government villages expressed higher levels of satisfaction (than those in dispersed housing) with their friendships and relationships (Gregory et al, 2001: 283).

Gregory's report lists a number of factors, which appear to be associated with increased levels of expressed satisfaction. Positive factors included:

- ◆ being independent and participating in domestic tasks,
- ◆ privacy and pleasant surroundings
- ◆ being with friends and friendly staff, and
- ◆ not being with aggressive and noisy co-residents.

Factors relating negatively to user satisfaction included:

- ◆ lack of money,
- ◆ Being with incompatible co-residents,
- ◆ Isolation and harassment by people in local communities,
- ◆ Institutional constraints on preferred lifestyles, and
- ◆ poor food.

(Gregory et al 2001: 280)

The following sections examine some of these factors.

2. Community integration and friendship patterns.

There is a significant body of literature, which has examined the process of deinstitutionalisation in the various countries where this policy has been pursued. This paper will not attempt to summarise this work. This section looks at evidence to assess whether community integration is substantially less among village residents than those in dispersed housing, and whether residents of villages have bigger or different friendship patterns. Although no research evidence has been found, this section notes villages for people with intellectual disabilities have sometimes been criticised as perpetuating many values which are inconsistent with person centred care and the right of people with a disability to be part of the community (CASL, 2000). Advocates for supported living say that to (have a chance to) be part of the community you must be in the community and that, by implication, villages do nothing to change old patterns of prejudice and isolation of the community towards people with a disability (Poll, 2002). The old pattern of care has been described:

“Residential facilities housing the more severely disabled were usually located in remote areas, with staff and residents living within the grounds, which residents very rarely left. Family members and friends were not encouraged to visit for fear of interrupting normal routines and all social interactions were with staff or other residents.” (Ralph and Usher 1997:163).

In an Australian study of deinstitutionalisation, Picton et al (1997) highlight the distinction between physical presence and participation in the community. While the majority of relocated clients in their study reported being happier in the community, they were also reported as having very fragile and limited support networks; minimal connections to significant others in the community; and having to rely primarily on the service system (paid staff) as a source of social contact. While almost all clients did have some access to community-based activities and resources, and actively attended a range of social activities with a recreation/leisure focus, participation did not lead to the development of meaningful interpersonal relationships with other members of the community (Picton et al, 1977:28).

Emerson's study also found that the size of social networks for all groups was small (4 to 7 people) with almost half being members of staff (Emerson et al, 1999: 64). After adjusting for differing levels of ability, people in non-government villages and dispersed housing had significantly larger networks than those in NHS villages and people living in dispersed housing were more likely than those in the two types of villages to have a person identified in their social network who did not have a learning disability, was not a relative and was not a paid carer. They were also likely to have experienced a greater number of recreational or community based activities in the previous four weeks. (Emerson et al, 1999: xv)

Gregory's report concludes that "increased satisfaction with friendships and relationships was associated with users having both more and a greater proportion of people with an intellectual disability in their social networks. These findings are consistent with the existing literature, which indicates that

- few people with an intellectual disability in residential care have meaningful relationships with people who do not have an intellectual disability, are not a member of their family and are not paid to be with them.
- there is little evidence that such ties develop over time while people live in community-based housing.
- people with an intellectual disability themselves place significant value on their friendships with other people with an intellectual disability". (Gregory et al, 2001, 289).

In their work comparing people in Australian inner, outer suburban and country dwellings, Ralph and Usher conclude that the move from large institutional settings to smaller, community-based homes has not, in and of itself, produced increased integration. (Ralph and Usher, 1997:166) They identify three inter-personal variables that are important in establishing well functioning relationships: proximity, opportunity and common interest.

“ Merely closing the institutions and transferring clients and staff into community-based settings will not ensure successful integration. Staff need new skills, new values and new goals if they are to succeed. They therefore need new training.” (Ralph, and Usher, 1997: 171).

In summary, while there is a considerable body of research, which has found that people with intellectual disability leaving institutions generally experience a number of marked improvements in their quality of life, research has also generally found that their friendship networks remain small and limited to other people with intellectual disability and staff. Research in the UK suggests that residents of villages do not have larger social networks than those in community housing and are more reliant on staff for their friendships.

3. Safety

Safety has been identified as an important issue for people living in retirement villages so it is no wonder that it is also an issue for those concerned about the well being of people with an intellectual disability, who are particularly vulnerable.

“For many respondents, the primary virtue of living in a retirement village appears to be the high level of personal and physical security the village provides, while at the same time allowing residents to retain a high level of independence.”
(Eardly and Birch 1998:79)

Moreover, intellectually disabled people have been found to be a high-risk group with respect to both personal and household crimes. In Australia, for personal crimes overall, victimisation rates were over 2.5 times greater for people with intellectual disability. They were also more than ten times more likely to be robbed than people without disabilities, and nearly three times as likely to be assaulted (Conway et al, 1996: 28-29). To examine the relative risks of alternative accommodation types, research findings were sought on whether abuse was carried out by strangers or other residents, and whether abuse occurred ‘in the community’ or ‘in house’.

Emerson’s UK study collected information on actual accidents, abuse and crimes and on perceived risks. Of 6 aspects studied, they found that non-government villages offer benefits (compared to NHS villages and dispersed housing) of lower rates of (documented) verbal abuse and crime (Emerson et al, 1999: xii).

An Australian study by Conway et al (1996) asked family and staff to provide information on three incidents they considered to be abusive. As well as type of abuse, data was gathered on who was responsible for the abuse. Family members identified Staff as responsible for 51% of incidents of abuse and fellow residents 21%. Each of the other groups of people (eg strangers) was responsible for less than 10 % of abuse incidents (Conway et al, 1996:122). The findings from staff were similar (staff being seen as responsible for 48% of the incidents and other residents responsible for a further 27 %). Both staff and family indicated that physical abuse made up more than half of the incidents of abuse from fellow residents.

Conway's report concludes “The perception that strangers are a major group in abusing clients was not upheld (4% for both questionnaires.)” (Conway et al, 1996: 110), particularly relative to the risk of abuse from fellow residents.

4. Costs

A report by Cox and Pearson, putting forward “the case for a Government policy which would support the creation of more Village Communities to care for mentally handicapped people”, did much to generate further research in stating:

“there is overwhelming evidence to indicate that village communities operate at a fraction of the cost of other forms of residential provision ‘in the community’, under the Government’s Community Care policy” (Cox and Pearson, 1995: 13).

Subsequent research has identified some of the factors determining costs, but even after efforts to control for the different support needs of residents and the quality of care and programs there are still large unexplained variations in costs.

One UK study of costs and quality of care involving 150 randomly selected facilities found that:

- Economies of scale were not apparent in facilities larger than 6 beds. In smaller facilities, the effect of size on costs was unclear, clouded by other factors such as the dependency of clients.
- Differences in the characteristics of clients (age and disability level) were the most important factors, which explained differences in the cost of residential services.
- Facility characteristics such as the number of places, the type of building, the range of services provided, the internal layout and environmental quality were not significantly related to costs (Raynes et al, 1994: 80).

Emerson’s study found:

“Comparisons of the costs of care associated with non-government villages and dispersed housing schemes provided conflicting results. When statistical procedures were used to control for differences between the two models with regards to the ability of the people supported, the total costs of care associated with non-government villages were significantly less than those associated with dispersed housing schemes. ... However, when comparisons were made on the basis of sub-samples selected by matching pairs of participants on the basis of ability, differences in cost between the two approaches were not statistically significant.” (Emerson et al, 1999: 111)

Cost per resident in NHS villages was found to be approximately 12 % lower than in dispersed housing schemes, but, the authors note, this cost difference is associated with a lower quality of care. “Determining whether additional costs are *justified* on the basis of improvements in quality is not, of course, a question amenable to scientific scrutiny.” They go on to state, however, that the additional cost of dispersed housing (compared with NHS villages) is associated with such benefits as: a 31% increase in staffing ratios; a 46% decrease in the rated level of institutional practices; a 52% decrease in the use of

anti-psychotic medication; a 55% increase in the size of people's social networks (p, 111).

In summary, although the small number of non-government villages (three) in the Emerson report provides grounds for caution, the evidence suggests that once allowance is made for differing care needs of residents, there are few cost differences between dispersed housing and villages. This is consistent with the UK White Paper's statement that there is no significant cost difference between non-government villages and dispersed housing (Valuing People, 2001:71).

Summary of research review

From the initial review of the accommodation literature a number of conclusions can be drawn:

1. The way in which services are resourced and managed as well as the quality of staff, more than the layout of the accommodation, affects the quality of life experienced by residents.
2. Making comparisons on the basis of satisfaction levels can be problematic when people have not lived in other types of accommodation.
3. Across the range of accommodation types residents generally had limited support networks and minimal connections to others in the community. However people living in dispersed housing were more likely to have a person without a disability who was not a staff, or family member as part of their social network. Residents of non-government villages tended to have more staff as part of their social network.
4. Given the most common sources of abuse of people with disabilities are from staff, other residents and families, it is difficult to argue that village housing is likely to expose residents to less risk of abuse than dispersed housing or cluster. Indeed the larger the living situation in terms of staff and other residents the greater potential there is for abusive relationships to occur.
5. In relation to costs the limited evidence available shows no statistically significant differences between the different types of accommodation if quality and needs are taken into account.

Whilst we need to be careful with considering overseas experiences, given the differences in our systems, as both styles of accommodation are currently in use in the United Kingdom, it is worth considering the conclusions drawn by Emerson et al (1999) who have researched extensively in this area.

Emerson et al (1999) question the suggestion that the development of villages on hospital sites represents a highly cost-effective redevelopment option. "when judged on the basis of likely **quality**, there is a very strong case indeed to suggest that *the process of hospital closure should be completed by the reprovision of the remaining hospital-based services within small community-based dispersed housing schemes.*" (Emerson et al, 1999: Summary report, 18).

Indeed as part of the research undertaken by Emerson et al (1999) all the accommodation organisations:

“were also asked what their ideal service would be, if they were starting from scratch. Responses were almost unanimous across all participating organisations, no matter, which service model, the organisation was currently managing. Organisations would ideally be providing smaller homes based in local community settings, led by the needs and wishes of residents, with access to comprehensive primary health care services and domiciliary care if needed.” (Emerson et al 1999: 13)

However, many of the reservations about village developments do not apply to cluster housing, where people with a disability can be living in the community, in close proximity to support staff and significant others and in accommodation which is varied in architectural style.

Clearly more work needs to be done if there are to be improvements in the extent to which accommodation arrangements help meet the social needs of residents and help them to become more a part of the local community. While research findings so far have not revealed anything inherent in the village style of accommodation that offers the potential for a greater quality of life than living within the community, having community residential units within ‘networking distance’ of each other maybe one way of achieving this objective. There is also a case for exploring the use of smaller living environments where one or two residents live together or in close proximity to each other and have staff nearby.

Responses to the discussion paper.

In June 2002 OPA convened three meetings with interested groups to provide an opportunity for response to the accommodation options paper. This section attempts to summarise the major issues discussed with parents (from Kew Cottages and Colanda), representatives from the Department of Human Services, and a number of disability advocacy groups. While there were a wide range of issues raised at the meetings, a review of the key points raised suggests there were three common issues on which there was broad agreement and one which remained an issue of contention.

Tentatively, there were three major points on which there was widespread agreement:

1. Planning decisions and service provision should recognise the differing needs and preferences of people as individuals. Services and accommodation should be person centred and flexible, recognising and making provision for needs that can change over time. There should also be a variety to provide individuals with an intellectual disability, or their guardians, with some choice on important issues, such as who to live with, and

2. The availability and quality of staff and specialist services (their attitudes, training, experience with intellectual disability, turnover) is of crucial importance in determining the quality of care of residents, no matter what their accommodation arrangements.

3. More consideration needs to be given to the needs and accommodation options of people with 'challenging behaviours'. This term can include a varied range of behaviours: each with implications for such things as suitability to live with others, need for secure accommodation, support needs and potential for community inclusion. It was recognised that some behaviours are a response to institutional living and that the right accommodation and support arrangements can result in marked changes in behaviour.

The major issue on which there was disagreement was the assessment of the practicality, even desirability, of the meaningful inclusion of people with intellectual disability into local communities. While there was broad recognition that inclusion in the community has not generally followed deinstitutionalisation, some parents groups at the discussion tended to maintain that arrangements, which promote interaction with peers and staff, would be more effective in promoting the well-being of residents. Other groups state that the goal of inclusion in the community should be an important part of support programs and can be achieved. This appeared to reflect differing perceptions of disability amongst the various groups.

In summary these discussions highlighted key elements of a good quality accommodation and support system, whilst also raising divergent views on the possibility and desirability of greater inclusion in the wider community for people with a disability. These views of disability and inclusion, influenced the type of accommodation preferred, together with questions around safety and limitations on personal behaviour in the group home context.

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